

106TH CONGRESS
2D SESSION

H. R. 762

AN ACT

To amend the Public Health Service Act to provide
for research and services with respect to lupus.

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1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Lupus Research and
3 Care Amendments of 2000”.

4 **SEC. 2. FINDINGS.**

5 The Congress finds that—

6 (1) lupus is a serious, complex, inflammatory,
7 autoimmune disease of particular concern to women;

8 (2) lupus affects women nine times more often
9 than men;

10 (3) there are three main types of lupus: sys-
11 temic lupus, a serious form of the disease that af-
12 fects many parts of the body; discoid lupus, a form
13 of the disease that affects mainly the skin; and
14 drug-induced lupus caused by certain medications;

15 (4) lupus can be fatal if not detected and treat-
16 ed early;

17 (5) the disease can simultaneously affect var-
18 ious areas of the body, such as the skin, joints, kid-
19 neys, and brain, and can be difficult to diagnose be-
20 cause the symptoms of lupus are similar to those of
21 many other diseases;

22 (6) lupus disproportionately affects African-
23 American women, as the prevalence of the disease
24 among such women is three times the prevalence
25 among white women, and an estimated 1 in 250 Af-

(7) it has been estimated that between 1,400,000 and 2,000,000 Americans have been diagnosed with the disease, and that many more have undiagnosed cases;

(8) current treatments for the disease can be effective, but may lead to damaging side effects;

(9) many victims of the disease suffer debilitating pain and fatigue, making it difficult to maintain employment and lead normal lives; and

(10) in fiscal year 1996, the amount allocated by the National Institutes of Health for research on lupus was \$33,000,000, which is less than one-half of 1 percent of the budget for such Institutes.

17 SEC. 101. EXPANSION AND INTENSIFICATION OF ACTIVI-
18 TIES.

Subpart 4 of part C of title IV of the Public Health
Service Act (42 U.S.C. 285d et seq.) is amended by insert-
ing after section 441 the following section:

23 “SEC. 441A. (a) IN GENERAL.—The Director of the
24 Institute shall expand and intensify research and related
25 activities of the Institute with respect to lupus.

1 “(b) COORDINATION WITH OTHER INSTITUTES.—

2 The Director of the Institute shall coordinate the activities
3 of the Director under subsection (a) with similar activities
4 conducted by the other national research institutes and
5 agencies of the National Institutes of Health to the extent
6 that such Institutes and agencies have responsibilities that
7 are related to lupus.

8 “(c) PROGRAMS FOR LUPUS.—In carrying out sub-
9 section (a), the Director of the Institute shall conduct or
10 support research to expand the understanding of the
11 causes of, and to find a cure for, lupus. Activities under
12 such subsection shall include conducting and supporting
13 the following:

14 “(1) Research to determine the reasons under-
15 lying the elevated prevalence of lupus in women, in-
16 cluding African-American women.

17 “(2) Basic research concerning the etiology and
18 causes of the disease.

19 “(3) Epidemiological studies to address the fre-
20 quency and natural history of the disease and the
21 differences among the sexes and among racial and
22 ethnic groups with respect to the disease.

23 “(4) The development of improved diagnostic
24 techniques.

1 “(5) Clinical research for the development and
2 evaluation of new treatments, including new biological
3 agents.

4 “(6) Information and education programs for
5 health care professionals and the public.

6 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the
7 purpose of carrying out this section, there are authorized
8 to be appropriated such sums as may be necessary for
9 each of the fiscal years 2001 through 2003.”.

10 **TITLE II—DELIVERY OF** 11 **SERVICES REGARDING LUPUS**

12 **SEC. 201. ESTABLISHMENT OF PROGRAM OF GRANTS.**

13 (a) IN GENERAL.—The Secretary of Health and
14 Human Services shall in accordance with this title make
15 grants to provide for projects for the establishment, oper-
16 ation, and coordination of effective and cost-efficient sys-
17 tems for the delivery of essential services to individuals
18 with lupus and their families.

19 (b) RECIPIENTS OF GRANTS.—A grant under sub-
20 section (a) may be made to an entity only if the entity
21 is a public or nonprofit private entity, which may include
22 a State or local government; a public or nonprofit private
23 hospital, community-based organization, hospice, ambula-
24 tory care facility, community health center, migrant health

1 center, or homeless health center; or other appropriate
2 public or nonprofit private entity.

3 (c) CERTAIN ACTIVITIES.—To the extent practicable
4 and appropriate, the Secretary shall ensure that projects
5 under subsection (a) provide services for the diagnosis and
6 disease management of lupus. Activities that the Secretary
7 may authorize for such projects may also include the fol-
8 lowing:

9 (1) Delivering or enhancing outpatient, ambula-
10 tory, and home-based health and support services,
11 including case management and comprehensive
12 treatment services, for individuals with lupus; and
13 delivering or enhancing support services for their
14 families.

15 (2) Delivering or enhancing inpatient care man-
16 agement services that prevent unnecessary hos-
17 pitalization or that expedite discharge, as medically
18 appropriate, from inpatient facilities of individuals
19 with lupus.

20 (3) Improving the quality, availability, and or-
21 ganization of health care and support services (in-
22 cluding transportation services, attendant care,
23 homemaker services, day or respite care, and pro-
24 viding counseling on financial assistance and insur-

1 ance) for individuals with lupus and support services
2 for their families.

3 (d) INTEGRATION WITH OTHER PROGRAMS.—To the
4 extent practicable and appropriate, the Secretary shall in-
5 tegrate the program under this title with other grant pro-
6 grams carried out by the Secretary, including the program
7 under section 330 of the Public Health Service Act.

8 **SEC. 202. CERTAIN REQUIREMENTS.**

9 A grant may be made under section 201 only if the
10 applicant involved makes the following agreements:

11 (1) Not more than 5 percent of the grant will
12 be used for administration, accounting, reporting,
13 and program oversight functions.

14 (2) The grant will be used to supplement and
15 not supplant funds from other sources related to the
16 treatment of lupus.

17 (3) The applicant will abide by any limitations
18 deemed appropriate by the Secretary on any charges
19 to individuals receiving services pursuant to the
20 grant. As deemed appropriate by the Secretary, such
21 limitations on charges may vary based on the finan-
22 cial circumstances of the individual receiving serv-
23 ices.

24 (4) The grant will not be expended to make
25 payment for services authorized under section

1 201(a) to the extent that payment has been made,
2 or can reasonably be expected to be made, with re-
3 spect to such services—

4 (A) under any State compensation pro-
5 gram, under an insurance policy, or under any
6 Federal or State health benefits program; or

7 (B) by an entity that provides health serv-
8 ices on a prepaid basis.

9 (5) The applicant will, at each site at which the
10 applicant provides services under section 201(a),
11 post a conspicuous notice informing individuals who
12 receive the services of any Federal policies that
13 apply to the applicant with respect to the imposition
14 of charges on such individuals.

15 **SEC. 203. TECHNICAL ASSISTANCE.**

16 The Secretary may provide technical assistance to as-
17 sist entities in complying with the requirements of this
18 title in order to make such entities eligible to receive
19 grants under section 201.

20 **SEC. 204. DEFINITIONS.**

21 For purposes of this title:

22 (1) The term “official poverty line” means the
23 poverty line established by the Director of the Office
24 of Management and Budget and revised by the Sec-

1 retary in accordance with section 673(2) of the Om-
2 nibus Budget Reconciliation Act of 1981.

3 (2) The term “Secretary” means the Secretary
4 of Health and Human Services.

5 **SEC. 205. AUTHORIZATION OF APPROPRIATIONS.**

6 For the purpose of carrying out this title, there are
7 authorized to be appropriated such sums as may be nec-
8 essary for each of the fiscal years 2001 through 2003.

 Passed the House of Representatives October 10,
2000.

Attest:

Clerk.